

Understanding the liver transplant process.

Information for veterans.



It's how we treat people.

Why choose MedStar Georgetown Transplant Institute and the DC VA Medical Center?

If you've been diagnosed with liver disease, choosing an experienced, multidisciplinary team of liver specialists with access to the latest diagnostic tools and medical and surgical treatment options is the first step towards managing your condition and living a healthier life.

The Washington DC VA Medical Center is one of seven VA hospitals in the country to offer liver transplant. The VA is partnering with the MedStar Health team at MedStar Georgetown Transplant Institute to offer excellent care for our veterans right at their doorstep. MedStar Georgetown Transplant Institute is Washington, D.C.'s largest academic liver disease treatment program and the area's leading liver transplant program. We make receiving care and communication with our team convenient, with offices located throughout the D.C., Maryland, and Virginia area.



Our team: Jessica Davis, MD, VA Director for liver transplantation; Rohit Satoskar, MD, Director of Medical Services, MedStar Georgetown Transplant Institute; and Atoosa Rabíee, MD, VA Medical Director of Solid Organ Transplant.

On the cover: Veteran Steven P. is grateful for the liver transplant that saved his life.

DC VA Medical Center Liver Transplant team

Physicians

Dr. Jessica P. E. Davis Dr. Atoosa Rabiee



Phone numbers

Medical Advice Line: 202-745-CARE

Liver transplant coordinators

Carole Daley, RN, **202-745-8000**, **ext. 57413** Crystal Fitzhugh, RN, **202-745-8000**, **ext. 56709**

Appointment scheduling

202-745-CARE (2273), ext. 55026

Liver transplant fax

202-745-8668, attn. Liver Clinic

Fisher House: Stacy Childs, 202-745-2482

Crisis Hotline: 1-800-273-8255

Billing: 202-725-8000, opt. 6, then press 1

Questions?

Find more information about the VA National Transplant Program at our website: va.gov/health/services/transplant.

Important things to remember

- 1. **No alcohol.** You will be asked to complete random testing for alcohol. You may be asked to attend an alcohol treatment program. **If you continue to drink alcohol, you could be taken off the list permanently.**
- 2. **No smoking.** The longer the time between stopping smoking and transplant, the better. Continued smoking leads to more problems after surgery and increases the risk of heart attacks, strokes, and cancers after transplant.
- 3. **No illegal drugs.** You will be drug tested and if illegal or un-prescribed drugs are found, **you may be taken off the list.**
- 4. **Compliance is critical.** We will explain how to take your medications and when to return for appointments. It is very important that you follow the instructions you are given to best manage your liver disease.
- 5. **Social support is necessary.** Immediately after the transplant you will need to rely on your family and friends for help. It is important to have someone with you at home while you are recovering to help with medications, clinic visits, and assistance with daily tasks. While you are listed, it is important to notify us if there are significant changes in your support structure.
- 6. **Keep the team up to date about financial changes.** Notify your financial coordinator as soon as possible if you have a change in your insurance or any insurance or financial issue that could impact the success of your transplant.

I'm listed for liver transplant, what happens next?

How long will I have to wait?

Now that you are on the UNOS waitlist, the wait for a liver to become available can be as short as a few hours or several months to years. Waiting for a liver transplant can be a difficult and stressful process for you and your family. The transplant team will do everything possible to help you during this time. You are encouraged to continue your daily routine and lifestyle while you wait.

You are listed in UNOS with a MELD score based on your lab numbers. That score ranges from 6 to 40. The higher the MELD score, the sicker the patient, and the higher she or he will be on the transplant waiting list. Livers are matched by blood type (A, B, O, AB) and size and are distributed based on distance from the donor hospital.

It is very important to keep your transplant team updated. Make sure that the team has every possible telephone number for you and your family members so that we can get in touch with you when a donor organ becomes available. If you wish to travel, let the team know the date of your travel and a number where you can be reached. If you become sick and are hospitalized, notify your transplant team as soon as possible. Remind your doctors to share any records, tests, or lab results with the transplant team so that we will have the most current medical reports regarding your care. You will be followed closely by both your VA and MedStar Georgetown Transplant Institute teams.



Jessica Davis, MD, reviews transplant information with a patient.



Juan Francisco Guerra, MD, specializes in living liver donation transplant surgery.

Living donor liver transplant

There are 14,000 people waiting for a liver transplant in the US. Being on the waitlist does not guarantee that you will get a transplant. Some patients on the waitlist become too sick or may die while waiting. Living donor liver transplant is an alternative for patients who have a lower MELD score and are at risk for remaining on the transplant waitlist for a long time. Please visit **www.MedStarGeorgetown.org/LiverLivingDonor** for more information.

How often do I need to get lab work and other testing completed?

- Your MELD score determines how often you need lab work. You may be asked to complete lab work once a week, once a month, or every 3 months. The higher your MELD score, the more often you will need lab work completed. Please notify your transplant coordinator when you have labs completed.
- Cardiac testing (stress test and/or echocardiogram) is required every 12 months.
- Abdominal imaging (MRI of the abdomen or CT of the abdomen) is needed every 6 months. If have liver cancer (HCC), abdominal imaging and a CT scan of your chest will be required every 3 months.

What are the organ transplant options?

Organ transplant by standard allocation/deceased donor

Deceased donor organs come from a person who has suffered brain death. Brain death means that there is no brain function, but the heart is still beating and blood is still flowing to all the body's organs. When an organ is available, medical data about the potential donor is entered into the UNOS computer system and a list of possible recipients is made.

The transplant centers with patients on the recipient list are then alerted. The transplant surgeon reviews the donor's information and decides whether to accept the organ based on medical data, organ condition, recipient condition, patient availability, and organ transportation. By policy, the transplant team has one (1) hour to make its decision. If the organ is declined, it will then be offered to the next patient on the list. This will be done until the organ has been placed.

- The donor has a history of hepatitis B. Even if someone has cleared the hepatitis B virus from their blood, small amounts of the virus could remain in their liver. If that liver is then transplanted, there is a chance that the hepatitis B virus could infect the recipient. It is safe for you to receive a liver from someone who may have been exposed to hepatitis B, but you will need to take extra medicine after transplant.
- The donor has a history of hepatitis C. If a donor has active hepatitis C, the transplant center might use this organ in someone who also has hepatitis C. These donor livers can also be offered to patients that do not have hepatitis C. If you do not have hepatitis C and accept one of these livers, you may then need to complete a course of treatment for hepatitis C. Before transplanting this liver, testing will be done, such as a liver biopsy to check that there is no damage to the donor liver from hepatitis C.
- **Donation after cardiac death (DCD).** Another pathway to organ donation is a process known as Donation after Cardiac Death (DCD). This is a family-driven process when a patient has non-survivable injuries and the family decides to withdraw support. The potential donor remains on a ventilator and medication so the organs can receive good oxygen and blood flow until the time of recovery for the potential recipients.

All organs are reviewed by the surgeon prior to transplant. Accepting a liver is based on your needs at the time the liver is offered. The transplant surgeon may advise you to consider accepting a liver from the groups listed above based on your medical condition.

The decision to accept organs must be weighed against the risk of dying or becoming sicker while on the waiting list. Taking part in this transplant option is fully voluntary. You will always have the choice to turn down a donor liver at the time it is offered to you. Please remember that we will not offer you an organ unless we believe it a good option for your circumstances. If you turn down an organ, it will not affect your rank on the UNOS wait list.

I have an organ offer!

Once a donor organ match has been made, the transplant coordinator will call and go over the organ offer with you. There are two different calls that you may receive—you will either get a call that you are primary (first in line) for an organ offer or back up for an organ offer.

If you accept the organ offered, the coordinator may give you these instructions:

- You will be told to not eat or drink anything from that point on.
- If you are at home, you may be asked to come to MedStar Georgetown University Hospital. You will go to the admitting office or another location depending on the time of day.
- Your vital signs (temperature, pulse, blood pressure, and respiration) and weight will be taken on admission. A doctor will give you a physical examination. An intravenous line (IV) will be started in your arm, blood will be drawn, and you will be asked for a urine sample. A chest X-ray and EKG (Electrocardiogram) will be
- You will be given surgical soap to clean your arms, abdomen, and groin area.
- You will be asked to sign a surgical consent form and the complications and risks of surgery will be reviewed with you.
- Once it is time for your surgery, you will be assisted onto a stretcher and wheeled down to the operating room.

In some cases, if the quality of the organ is not good, the transplant may be cancelled. If this happens, you will be notified by a member of the transplant team and discharged.

If you were called regarding a backup offer, you will get a call from the coordinator either asking you to come to the hospital or that you have been released as back up and will continue to await other offers. This process could take 24 hours and you can always call the on-call coordinator for an update.



Veteran John, liver transplant recipient, with Dr. Rabíee.

To begin the process, ask your VA PCP for a referral to the DC Liver Clinic, or call **202-745-CARE** (2273).

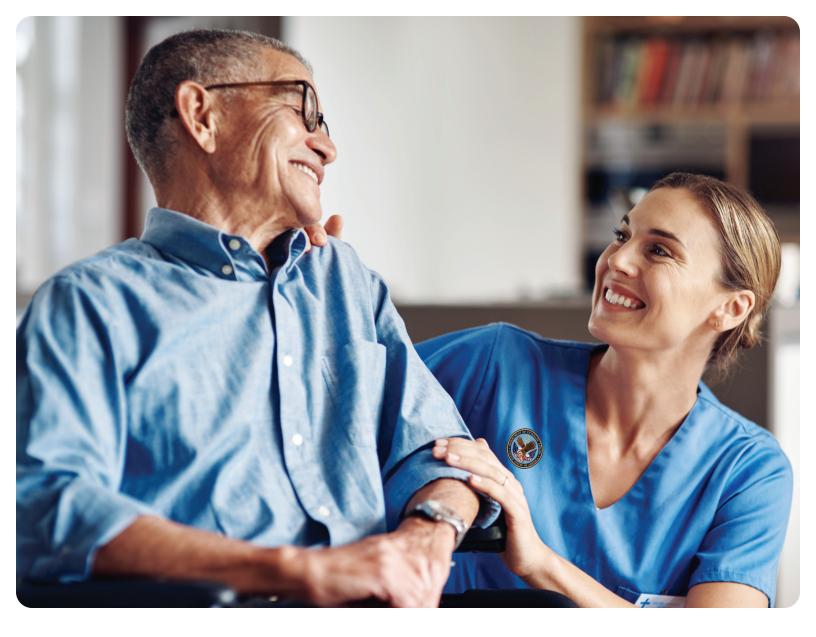
What are the possible complications of liver transplant?

There are risks with all surgeries, and liver transplant is one of the most complex surgeries. Most complications are minor and improve with time. In some cases, the complications are serious enough to require another surgery or medical procedure. Rarely, complications may result in death.

- After surgery, you may experience pain. Most patients have a major decrease in pain several weeks after surgery. Some people may still have discomfort for a longer time.
- There may be a delay before your new liver starts to function. This may increase the length of your hospital stay and the risk of other complications. There is a rare possibility that the transplanted liver will not function. If this happens, a second transplant would be needed. You would be put back on the waiting list in the highest priority category.
- Hepatic artery thrombosis (a clot in the major blood vessel going to the liver) can happen in a small number of liver transplant cases. It may cause two types of complications including an abscess in the liver and/or biliary strictures (narrowing of the bile ducts). If this happens, other procedures, additional surgery, or a second liver transplant may be needed.
- Some patients may have long term complications from biliary strictures. Bile is a secretion of the liver that helps with the breakdown of food and digestion. A stricture is a narrowing of the ducts moving that bile. Most of these strictures can be corrected by placing a stent (small tube) into the bile duct. This will prevent any further narrowing and allow the bile to move. Some patients may need surgery to repair the damaged bile ducts.



Atoosa Rabíee, MD, explaining the process.



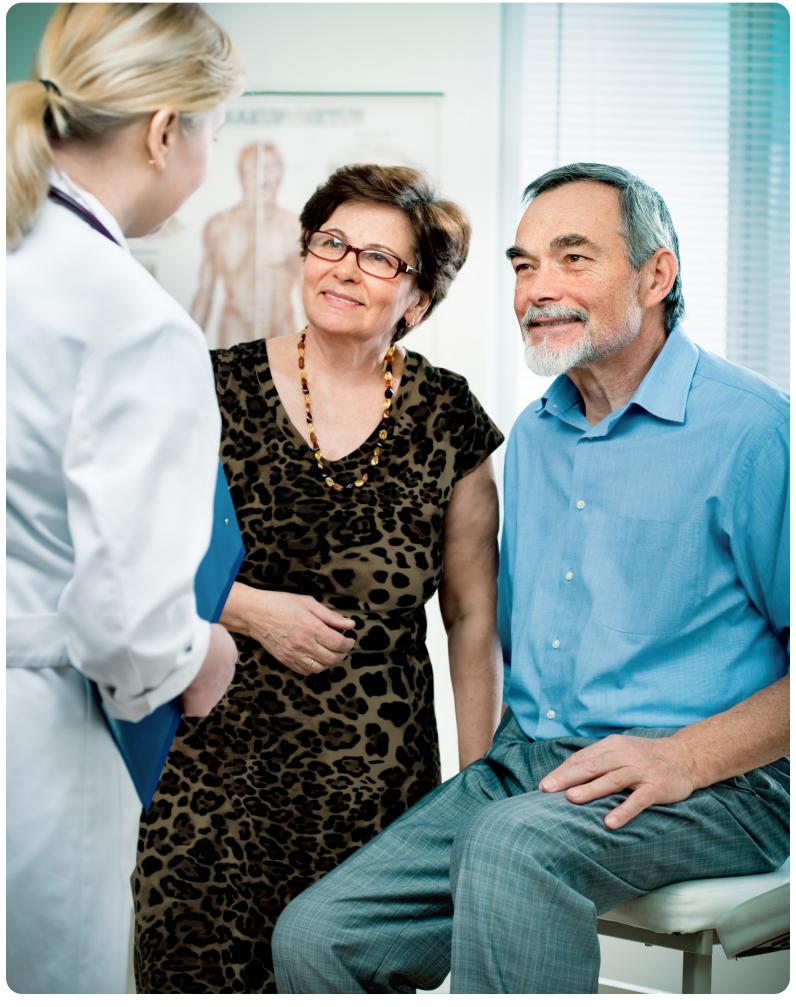
- Some patients may have bile leaks. Fortunately, most bile leaks can be fixed without surgery. These leaks can usually be treated by placing a stent in the bile duct. Occasionally (if endoscopic treatment is not possible or successful), a small tube will be placed through the skin into the bile ducts to help drain the bile while the leak heals.
- After surgery, the transplant team will closely monitor you for signs and symptoms of infection. If an infection happens, the infectious disease team will work with the transplant team to quickly develop the best treatment plan.
- Intravenous (IV) lines may need to be changed during your hospital stay. This lowers the risk of an infection occurring from these lines. The lines will be removed when you are eating regularly and no longer receiving intravenous medications.
- Blood clots are a concern after surgery. When they occur, they usually develop in the legs. The clot can break free and move through the heart to the lungs. When the clot moves into the lungs, it can cause serious trouble breathing, which can lead to death. Blood clots are treated with blood thinning medications, which need to be taken for a long period of time to lower the risk of any other clots forming.
- Bleeding can happen during or after surgery. You may require blood transfusions or blood products.
- Nerve injury may occur due to positioning of arms, back, or legs during the surgery. Signs and symptoms of nerve damage are numbness, weakness, or pain. Most of the time symptoms are temporary and resolve with time. Occasionally, the symptoms become long-lasting.

What will it be like when I wake up after surgery? The Intensive Care Unit

After surgery, you will be in the Intensive Care Unit (ICU) for several days. In the ICU, you will see and hear a variety of monitors and equipment. The monitors will measure your vital signs, such as heart rate and blood pressure. Below is a list of some of the other equipment that you will see or experience during your ICU stay:

- **Nasogastric tube:** This tube will go through your nose into your stomach and will drain the acids that your stomach makes. It will prevent you from becoming nauseated. It will be taken out when your bowel function returns and then you will be able to eat.
- **Breathing tube (endotracheal tube):** This tube will be placed while you are in the operating room. The tube will come out of your mouth and attach to a breathing machine or ventilator. The machine will assist your breathing while you are under anesthesia until you are awake. The tube will be removed once you are fully awake.
- **Urinary catheter:** This will be put in during surgery to let you urinate. You may feel the need to pass urine, but the catheter will drain the urine out of your bladder. This catheter will only be in place a few days.





- Intravenous (IV) lines: You will have multiple lines going into your veins. These lines will be used to give fluids, nutrition, and medications until you are able to take them by mouth.
- **Drains:** You will have several small tubes coming from your incision site. These tubes are used to collect fluid drainage from the wound. The tubes will be taken out when the amount of drainage fluid decreases.
- **Blood clot prevention devices:** You will have alternating inflating stockings on your legs. They will be used to help increase the blood flow in your legs and prevent blood clots.
- Patient safety devices: Patients have different reactions to anesthesia. After surgery it may be necessary to use safety devices, so you do not hurt yourself or dislodge your tubes. These may be used until you are fully awake.

The ICU can be a noisy place filled with activity. This can be stressful for patients. Your ICU nurse will make your time in the unit as comfortable as possible. You will only stay in the ICU about two to five days, until you no longer need continuous monitoring. You will then be moved to the general transplant unit.

Care on the General Transplant Unit

Once you are on the general transplant floor (6-Bles), you will be encouraged to cough and deep breathe to decrease the chance of developing lung complications. It will be important to get out of bed at least three times a day to walk around your room and down the halls. Walking will help to increase the blood moving through your body and keep your muscles strong.

Follow-up care after discharge

Once you are released from the hospital, you will have frequent clinic visits and blood tests. You must stay in the local area (within a few hours of Washington, DC) for six to 12 months after the transplant. You will be seen at the MedStar Georgetown Transplant Institute clinic for the first three months after transplant and then return to the DC VA Liver Clinic for ongoing care. You will be provided with a medication plan and daily diary to record your weight, temperature, and blood pressure. You will need to be bring these tools to every follow up visit.

Lab work and clinic visits are one to two times a week to start. After the first three months, you will be seen once a month with lab work every two weeks. Once you are stable, you may be able to be seen in one of our clinics closer to your home. Patients are then seen every three months for six to 12 months following transplant, with monthly lab work. Lab work will then decrease to once every three months with yearly clinic visits. Long-term follow-up is managed by the Transplant Clinic and referring physicians.

You will continue to see your primary care physician. He or she will help manage your health for non-transplant issues. Your blood pressure, blood sugar, and cholesterol should be checked often. It is important that you continue a healthy diet and exercise after transplant to avoid gaining weight and let the transplant team know about any changes in your health.

For more information, visit Va.gov/health/services/transplant/ or MedStarGeorgetown.org/LiverTransplant.



FAQs about life after liver transplant

How long will my transplanted liver last?

Liver transplant recipients have been able to live a normal life for over 30 years after their transplant. Close follow up with your transplant team and primary care physician can help make your liver remains as healthy as possible. It is important to live a healthy lifestyle after transplant. This includes taking medications as prescribed, eating a healthy diet, taking part in regular exercise, and preventing infection.

What can I expect my quality of life to be after liver transplantation?

The first three months after transplant are the hardest. Your body is adjusting to the new liver and all the medications needed to keep it healthy. Once released from the hospital, you can care for yourself, with minor restrictions. Most patients can return to work within three to six months after a transplant. Going back to a normal life (playing sports, getting exercise, socializing, and traveling) after recovery is our goal.

Will my liver disease come back after a transplant?

Certain liver diseases can return in the new liver. The transplant team can go over the rate of return for different liver conditions. If there is a risk of the liver disease returning, the transplant team will monitor you very closely to help manage this risk.

How large is the scar?

The normal incision used for the liver transplant goes across the upper abdomen from right to left. There is also a short up and down incision starting under the sternum (breastbone). It is also known as a "Mercedes-Benz" incision or "peace sign".

How long is the recovery period?

Most patients are in the hospital for seven to 10 days after their liver transplant. Most patients generally recover at home and can go back to work or school after about three to six months.

Will I need to take medications after my liver transplant?

You will need to take many medications after liver transplant. Some medications prevent rejection (immunosuppressants), some fight infection, and others treat the side effects of the immunosuppressants. Patients returning home after transplant will take about seven to 10 different types of medications. As you heal and recover, the number of medications needed decreases over time. By six months, it is common to be down to one or two medications.

You will take certain medications for the rest of your life in almost all cases. It is very important that these medications are taken as prescribed, in the correct amounts, and at the specified times. Missing medication doses or stopping them can lead to rejection and organ failure.

What side effects can be expected from my medications?

Many medications have side effects. Common side effects of post-transplant medications include high blood pressure, changes in mood, hair loss or hair growth, elevated blood sugar, bone and muscle weakness, kidney problems, nausea, vomiting, diarrhea, and headache. You may experience side effects when starting the medicines. These side effects often improve over time as dosages are lowered. Though side effects can be bothersome, medications should never be stopped without discussing it with the transplant team. When side effects are serious, the medicines can be changed by your physician.

Can I return to work after my transplant?

Yes, you are encouraged to return to work after transplant. It takes around three to six months before it is possible to safely return to work. Certain patients will require light-duty assignments when they return to work. Disability is usually not granted for more than 6 months after a liver transplant. From the start of the transplant process, your long-term employment goal should be to return to work in a timely manner to avoid a gap in health insurance coverage.

Can I drink alcoholic beverages after my transplant?

No. Alcohol is toxic to the liver. It can also affect the absorption of certain medications. Non-alcoholic beers also often contain alcohol and are not recommended.

How can I get in touch with the family of my donor?

Transplant recipients often want to thank the donor's family for the liver they received. To communicate with the donor's family, write a letter without signing it and give it to the team's social worker at the transplant center, who will send it to the organ procurement agency. The agency will forward it to the donor's family. Often the donor's family will respond with an anonymous letter. Not everyone receives a response, but this does not mean your thanks was not valued by the donor's family.

MedStar Georgetown Transplant Institute provides evaluation, diagnosis, and treatment for patients suffering from a variety of liver disorders.

We make getting the care you need as easy as possible. Patients can use our secure, easy-to-use online portal, **myMedStar.org**, to access medical records, set up appointments, check test results, email doctors, request prescription refills, share medical records with other doctors, and pay hospital and doctor bills.

MedStar Georgetown University Hospital

3800 Reservoir Rd., NW 2nd Floor PHC Washington, DC 20007

MedStar Washington Hospital Center

110 Irving St., NW POB South, Ste. 215 Washington, DC 20010



Washington DC VA Medical Center 50 Irving St., NW Washington, DC 20422



Washington DC Fisher House 50 Irving St., NW Washington, DC 20422

VA Fisher House

"A HOME AWAY FROM HOME"

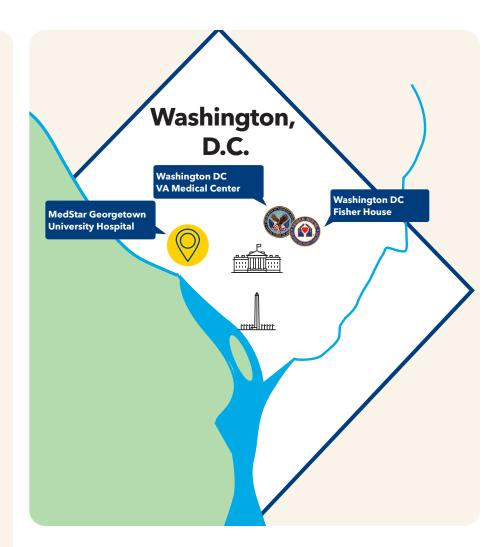
Fisher House provides high quality temporary lodging, at no charge, to families of Veterans who are undergoing inpatient or extensive outpatient treatment at the Washington, D.C., Veterans Affairs Medical Center. Fisher House is considered to be a "home away from home" and offers a warm, compassionate environment and a sense of comfort while a loved one is undergoing medical treatment.

Washington DC Fisher House 50 Irving St., NW Washington, DC 20422

Guests must be medically stable to care for themselves and/or family members independently, and must live 50 miles or more from the VA Medical Center. Referrals should be done in advance by the **Social Worker** or **Primary Care Physician** assigned to the patient.

In addition to a private bedroom, the house includes an in-room telephone; a TV/DVD player; in-room computer access and devices; a common kitchen; spacious common dining room; an inviting common family and living room; a common laundry facility; and outdoor pavilion.

For questions, please contact the Fisher House management at **202-745-2482.**



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MedStarGeorgetown.org/LiverTransplant



